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AUTHOR Naseef, Robert
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ABSTRACT

Seven functional families with handicapped children were studied using a case study approach. Through the qualitative paradigm, the development of successful coping mechanisms was examined. The parents completed an instrument called "CHIP, Coping Health Inventory for Parents," and all family members were interviewed. Subject families were recommended by professionals as coping successfully and also as containing at least one non-handicapped child. Disabilities represented were: deaf blindness, deafness, chronic illness, autism, learning disabilities, cerebral palsy, and emotional disturbance with learning disability. From the results of the case studies it was possible to draw three generalizations: first, these families developed a broad repertoire of coping mechanisms; second, the parents tended to have convergent accounts of how they coped; and third, the siblings interviewed all reported being able to freely question and discuss issues concerning the handicapped sibling. The paper proposes further investigation of three hypotheses: (1) there is a strong positive correlation between marital adjustment and satisfaction and ability to cope with a handicapped child; (2) there is a strong positive correlation between participation in a parent support group and ability to cope with a handicapped child and marital satisfaction; and (3) there is a strong positive correlation between parental ability to cope successfully and the psychological adjustment of their non-handicapped children. (DB)

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How Families Cope Successfully With a Handicapped Child: A Qualitative Study

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Robert Naseef, Ph.D.
Temple University

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Abstract

Seven functional families were intensively examined using a case study approach. Through the qualitative paradigm, the researcher was able to discover how they were able over time to develop successful coping mechanism. The parents completed an instrument called CHIP: Coping Health Inventory for Parents, and all family members were extensively interviewed about their experiences. Family members were found to have a broad repertoire of coping behaviors. Parents relied heavily on each other for support, and they strove to maintain family unity. In addition, three hypotheses evolved from this study, and these predictions can be tested quantitatively in future research.

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INTRODUCTION

This research focused on how families with an exceptional child can cope successfully. Having a handicapped child can place an inordinate amount of stress on family life. Since parents have a dream for their child in terms of who their child will be and what he or she may accomplish in life, the birth of a handicapped child shatters that dream. Parents are then faced with the dilemma of having to accept a child who will never be able to live up to their expectations. The siblings of a handicapped child likewise lose their dreams in terms of having a normal playmate or companion.

Aided by federal legislation, there has been a proliferation of services and educational programming for special needs children with the goal of helping them to develop to their fullest potential. The professionals involved in the planning and delivery of these services frequently have difficulties in communicating with parents who sometimes seem not to accept the reality of their child's condition. Both families and professionals can benefit from an understanding of how families can cope with the tragedy and the often frustrating reality of having an impaired child. This research study was therefore centered on families who had coped successfully with the outlook that the findings could benefit those struggling to cope as well as their professional helpers.

The hardships faced by families of exceptional children have been found to include strained relationships, modified goals and activities, increased financial burdens, social isolation, medical

problems, different educational arrangements, and grieving associated with the restricted life opportunities for the impaired child (McCubbin and Patterson 1983). It made sense, therefore, to look for answers from families who had dealt with these kinds of hardships and coped successfully.

Theoreticians have used the mourning process as a frame of reference to understand the reactions of parents to the diagnosis or discovery of an impaired child. This loss is similar to the loss of a loved one, a job, an ideal, etc. (Solnit and Stark, 1961). This loss of the ideal child has been generally understood to occur in stages which include feelings of anxiety, guilt, depression, and anger. Some clinicians have tended to view parents' chronic sorrow as a neurotic manifestation rather than as a normal response to a tragic situation.

Following the experience of grief, parents can focus outward, and at this point, it is theorized that adequate coping can begin (Fortier and Wanlass, 1984). Most studies that have been conducted to date have focused on the impact or stress that an exceptional child has on the family; therefore we know more about problems than solutions. There is, however, a small but significant body of literature that deals with successful adaptation and coping. It was the purpose of this study to add to that body of knowledge.

Another limitation of most previous research has been an almost exclusive concentration on the parent-child interaction which was usually operationalized as the mother - child interaction. Recently there has been a growing trend to look also

at the father and at the siblings and thus to conceptualize the exceptional child in the family context in which she or he lives and develops. This systemic view has become relatively common, and so each family member's behavior is seen as affecting the others' behavior as well as being affected by it (Minuchin, S. 1974).

In quantitative studies, the researcher focuses on selected predefined variables and through prediction and control seeks the causes and effects of human behavior. The qualitative researcher, on the other hand, seeks a holistic picture that includes people's interpretations and perceptions under natural conditions. Whereas the quantitative paradigm investigates predetermined hypotheses, the qualitative approach leads to the evalution of theories and hypotheses from the data as collected. Because of the complex nature of coping for the families of the handicapped, a qualitative approach was selected for this investigation.

METHODOLOGY

Subjects

The subjects for this intensive case study research were chosen carefully. They were recommended by professionals in the handicapped child's educational setting as "coping successfully without undue behavioral problems". The criteria for normal functioning were adopted from the literature on normal families (Riskin, 1982). The parents of these families also assessed themselves as coping successfully. Each family also contained at least one non-handicapped child of elementary school age or beyond.

Various exceptionalities were represented: a deaf-blind young adult, a deaf child, a chronically ill child, an autistic child, a learning disabled college student, a child with cerebral palsy, and an emotionally disturbed teenager with a learning disability. The families came from various socioeconomic backgrounds; two of the families were black; and one family was headed by a single parent.

Role of the Researcher

The researcher's role is an important issue in qualitative research, because the researcher both affects and is effected by the study. The researcher's identity as the parent of a handicapped child had a definite impact in this study. Possible bias due to the researcher's own life experiences was controlled through the use of a co-researcher in interviewing and data analysis and by the committee that supervised this doctorial research. On the other hand, the participants in the study responded openly, warmly, and enthusiastically to someone whom they regarded as a peer in terms of common experience. Several participants commented that they were able to be extremely frank in their interviews for this reason. They unanimously expressed the notion that they learned from the process of being interviewed especially in terms of putting their experiences in perspective. Likewise, the researcher was influenced personally as well as professionally by the research process in this study.

Procedures and Techniques

The methodology selected was based on multiple assessments of each family. Since this research is exploratory in nature, it was

expected that working hypotheses or themes could be generated that could be tested quantitatively in future studies. An instrument called CHIP: Coping Health Inventory for Parents (McCubbin et al., 1979) was selected to gather data about the coping behaviors employed by parents. This instrument was based on the Double ABCX Model of Family Stress (McCubbin and Patterson, 1983). This model makes it possible to look at a family's efforts to adapt to stress over time. The model focuses on resources and perceptual factors used by the family to develop new coping mechanisms designed to achieve and maintain family balance.

Since this model of coping involves thoughts, feelings, perceptions, and behaviors, the interview method was selected to gather this data intensively from each family member. One structured interview was devised for parents; another set of questions was designed for siblings; and a third set of questions was designed for the handicapped child whenever that individual was competent to be interviewed. The results of the CHIP were also used to help guide the interviews. A total of 31 individuals were intensively interviewed, including 13 parents, 13 siblings, and 5 handicapped children. Approximately two days were spent in the home of each family. All interviews were tape recorded and transcribed.

This data was then coded and the content analyzed with guidance from the ethnographic literature (Spradley, 1979, Miles and Huberman, 1984). Random selections from the transcripts of interviews were then analyzed by a co-researcher in order to corroborate the findings. Reliability was found to be .93, thus confirming the consistency of the data analysis.

Through the interviews and the CHIP instrument, the researcher was able to gather a rich collection of thoughts, feelings, attitudes, and behaviors. Through a careful analysis of this data, it was possible to draw conclusions and generate working hypotheses for future testing and to paint a picture of how families cope successfully with a special needs child on a day to day basis.

RESULTS

The CHIP results confirmed that these 13 parents have a repertoire of coping behaviors that is broader than the average of the normative sample that was used for the CHIP scales. This is what we would have expected to find in this sample of seven families who were recommended by professionals as coping well.

A clear majority of the fathers (4 or more) identified the following coping behaviors as extremely helpful to them:

1. Trying to maintain family stability.
2. Trusting my spouse to help support me and my children (identified by all six fathers).
3. Doing things together as a family (involving all members of the family).
4. Building a closer relationship with my spouse.
5. Talking over personal feelings and concerns with spouse.
6. Talking with other parents in the same type of situation and learning about their experiences.

A clear majority of the mothers (5 or more) identified the same six behaviors as extremely helpful to them plus two additional items:

7. Telling myself I have many things to be thankful for.

8. Doing things with my children.

Three clear themes emerged from these CHIP results. First, parents relied very heavily on their marital relationship as a source of support. As one mother stated, "Dealing with our son's handicaps brought brought me and my husband closer together because we really had to depend on one another. Only Jim could really understand what I was feeling and going through".

Secondly, parents found that other parents of handicapped children were extremely helpful to them. One mother reflected that, "I can talk to them better than to my best friend because they know what I'm talking about". A father stated, "For most people who haven't gone through this, the situations too horrible to talk about. They think about their own children and how horrible it would be for them... The only people you can really talk to about this are people who have been through this".

Third, maintaining family unity and stability was a key factor in coping successfully. This was succinctly described by a father who explained, "We tried to keep the overall family life as normal as possible, and then when Sally was ill we rallied around her".

A summary of how family members coped with day to day problems was prepared from the content analysis of the interview data (see Table I). Problems or concerns that recurred across the seven cases were grouped into categories for this summary.

Table 1

Summary of Coping with Day to Day Problems

Family Members	Type of Problem/ Feeling Involved	Solutions
Mother, Father	Acceptance of handicap (intial diagnosis)/Shock, Fear, Devastation	Observe Child, talk to spouse, exposure to other handicapped children, look for the positive in child, seek second opinion, religion/prayer, time healed, treat child as normally as possible, allow time to be sad, seek more information, learn to appreciate little accomplishments of the child.
Mothers, Fathers	Socialization of the handicapped child/Fear, Worry	Family becomes social group, professionals helped, Sibling helped.

Mothers, Fathers, Siblings	Communication with handicapped child/ Loneliness, Frustration	Depending upon the situation: learn sign languare, use telecaption divece, speak slowly, repeat yourself, understand limitations for all.
Mothers, Fathers	Siblings worry	Don't give them too much responsibility, talk about problems, keep family life as normal as possible, make each child special, be aware of feelings.
Mothers, Fathers, Siblings	Worries about future/ Fear	Talk and plan for the future.
Mothers, Fathers	Finding services/ Worry, Anger	Learn rights, become advocate for child.
Mothers, Fathers	Behavior management/ Frustration, Depression	Solve one problem at a time ask for help, learn from other parents.

Mothers, Fathers	Dealing with professionals/ Anger	Speak up, follow your instincts, seek other opinions.
Mothers	Dealing with self-blame, and other criticisms/Guilt	Take time to think things over, talk to other parents.
Mothers	Being overwhelmed/ Depression	Rely on spouse, get away for. relief, find babysitter.
Siblings	Questions about handicapped child/Worry	Talk to parents, visit special school or class, and talk to teachers.
Siblings	Other children don't understand/ Embarrassment, Anger	Explain to them, speak up if they tease
Special children	No one seems to understand/ Loneliness	Talk to other handicapped people, Counselors can help.

Special children	People teasing/ Embarrassment, Anger	Speak up.
Special children	Keeping up in school/Worry	Get help from family use school resources.

DISCUSSION

From the results of the seven case studies, it was possible to draw three generalizations about families that learn to cope successfully over time. First, these families developed a broad repertoire of coping mechanisms consistent with the Double ABCX Model of family stress. Besides resources that already existed before the initial diagnosis, new resources were developed in response to the increasing stresses and strains. Secondly, the parents tended to have convergent accounts of how they coped. This is what we would expect from functional families where members communicate with each other. Third, the siblings interviewed all reported being able to freely question and discuss issues concerning their handicapped sibling. Again this is what we would expect to find in functional families as described by Salvador Minuchin (1974) in systems where each member is affecting others' behavior as well as being affected by it.

All family members interviewed were unanimous in reporting positive effects from the experience of having an exceptional member. As individuals and as family units, they showed the ability to make some philosophical sense or meaning out of what had happened to them, and this was one of the factors that Venters (1981) found to be a predictor of successful coping as well as a component of the Double ABCX Model. Although having a handicapped child has frequently been seen as having a deleterious effect on the marriage (Longo and Bond, 1984), these families reported that having a handicapped child actually brought them closer together. So it is

not the handicapped child but how the family copes with stress that effects relationships within the family.

The siblings expressed the belief that they could be better parents because of witnessing how hard their own parents struggled. Perhaps the most common lesson reported by parents and siblings alike was that "It made us aware of which things are really important in life". Optimism, patience, and a sense of humor were vital qualities reported by most families as a valuable positive effect of their experience.

This research study yielded four main implications for practitioners. First, all seven families reported that it took them a period of several years to learn how to cope effectively. Families who are having difficulty with this process should be seen as groping for effective solutions as opposed to being seen as pathological. Next, being able to empathize with the family's plight was the key quality cited by family members as being most helpful to them. Third, setting up and maintaining support groups should be a high priority for practitioners based upon how vital parents found the support that they received from other parents of handicapped children. Finally, professional contact with siblings should be expanded based on the great benefit siblings reported from the limited contact they experienced with professionals.

Three hypotheses were generated for future research. The first hypothesis is that there is a strong positive correlation between marital adjustment and satisfaction and the ability to cope successfully with a handicapped child. Next, there is a strong positive correlation between membership and participation in a

parent support group and the ability to cope successfully with a handicapped child and marital satisfaction. Third, there is a strong positive correlation between parents' ability to cope successfully and the psychological adjustment of their non-handicapped children.

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